Subject: Urgent Request for Legislative Action on Rare Diseases – Support HB 2457

Dear Members of Congress,

- I was 8-years-old when I first learned I carried a 50% risk of a genetic terminal brain disease from my maternal ancestors.
- Later I became aware that Huntington's disease, for which I was at-risk, was coincidentally named after my paternal ancestors with the surname Huntington.
- In my lifetime, Huntington's disease has killed the majority of my maternal family- much of which has lived and died in Oregon, throughout Coos, Douglas, Klamath, and Polk counties
- Historically, Huntington's disease has killed relatives in three branches of my family. In some branches, the disease is no longer present.
- Invitro-fertilization, contraception, genetics counseling, education, stem-cell research and CRISPR technology are vital to preventing, treating or attempting to cure Huntington's disease; but somehow access to health care viewed as a political question, and while trying to survive we also have to advocate for our rights to do so and to manage our own health care decisions.

I am a descendant of Simon Huntington, who died of smallpox in 1633 on the way to the colonies, his widow and children settling in Massachusetts. Simon Huntington's descendants are prominent figures in United States history:

- Founding Father Samuel Huntington, signer of the Declaration of Independence, often referred to as the first true President of the United States as President of the Continental Congress, and US Supreme Court Justice;
- United States Congressmen:
    - Jabez W. Huntington (Connecticut)
    - Frederick Huntington (Massachusetts)
    - Benjamin Huntington (New York)
    - Abel Huntington (Ohio)
    - Terri Huntington (Kansas)
    - Samuel Huntington (Ohio)
    - Elisha Mills Huntington (Indiana)
- Collis Potter Huntington, railroad magnate and one of the "Big Four" of western railroading involved in establishing the Central Pacific Railroad, Southern Pacific Railroad, Chesapeake & Ohio Railway
- Zina Diantha Huntington Jacobs Smith Young involved in founding the Church of the Jesus Christ of Latter Day Saints
- The Huntington family of physicians from Long Island, NY who studied a rare, tragic, and terminal genetic brain disease that was bestowed the Huntington name, including Doctors Abel Huntington, George Huntington and George Lee Huntington
- Specifically, I descend from Simon's son Deacon Christopher Huntington and three subsequent generations of sons named Christopher.

I am writing to you today on behalf of my family, the Huntington family, and the countless others who are impacted by rare diseases in Oregon. Our family's history has been one of profound contributions to the fabric of American society—spanning industry, government, medicine, and religion. From Founding Father Samuel Huntington, a signer of the Declaration of Independence and President of the Continental Congress, to the Huntington family of physicians who first studied the genetic brain disease now known as Huntington's disease, our legacy is one of service and innovation. However, for all the strides we've made in other fields, there remains an urgent need to address the glaring disparities in care and resources for individuals and families living with rare diseases, specifically Huntington's disease.

Huntington's disease is a tragic and terminal genetic disorder that is passed down through families, with a 50% chance of inheritance. Despite being present from conception, it does not fit neatly into current disease classifications—it is neither a developmental disorder, an aging disorder, nor a mental health condition, though it can cause severe psychiatric and neurological symptoms. This lack of classification has left patients and families struggling to access proper care and support. Skilled nursing, occupational therapy, and speech therapy, essential for those suffering from Huntington's disease, are often denied once the diagnosis is known due to misconceptions about the disease.

Perhaps most alarming is that in Oregon, we have no comprehensive understanding of the prevalence of rare diseases, including Huntington's disease. Rare disease patients and families are not counted in our health care system, meaning their needs go unaddressed, their voices unheard. This exclusion has contributed to a healthcare system that fails to meet the needs of those living with rare diseases—those who are often faced with a lifetime of suffering, isolation, and a lack of vital services.

As a direct descendant of Simon Huntington, I am acutely aware of the legacy my family has created in the fields of healthcare, governance, and social progress in the United States.

I ask you, as stewards of this great nation, to stand with us. Please support the passage of **HB 2457**—a bill that will dedicate much-needed attention and resources to rare disease patients and families in Oregon. We need a system that not only acknowledges rare diseases but also actively works to improve care, services, and treatment options for those affected. We need a system that understands the magnitude of diseases like Huntington's, and the profound toll they take on families.

Did you know Oregon's population of 4.233 million people has only one Huntington's Disease Center of Excellence? It's at OHSU. Patients and families cannot always endure or afford travel to the far corner of the State, especially in advanced stage of disease. We need better access to neurological care and genetics counseling in this state, but that will never come if you don't even count rare disease patients as stakeholders in the healthcare system.

I urge you to vote **in favor** of **HB 2457** and to make a clear, meaningful commitment to supporting rare disease patients in Oregon and beyond. The time to act is now—our families, our communities, and our healthcare system cannot afford to wait any longer.

Thank you for your time and your attention to this urgent matter.

Sincerely,
Rebecca Ambrose

Salem, Oregon